

CHILDREN'S SERVICES CO-ORDINATING & ADVISORY GROUP

RESEARCH RESOURCE BODY

84- 2999 /

PARENT RELIEF STUDY RESULTS

A. Background

The need for parent relief services for mentally handicapped children in the Region was first addressed by the Oakville Association for the Mentally Retarded in April 19, 1982 when a Proposal for Parent Relief was prepared. This paper proposed a program providing parent relief for mentally handicapped children either in the child's home or the home of the Relief Provider.

This proposal was presented to the Children's Services Steering Group (CSSG) and in October 1982 the Technical Co-ordinating Sub Committee of the CSSG agreed that it was within its mandate to undertake a study of parent relief needs for all special needs children in the Region of Halton. Case Management Services, Sheridan College, agreed to conduct the study on a voluntary basis.

In December 1982 a questionnaire was sent to 53 agencies in Halton, Peel, Hamilton-Wentworth, and Toronto and all data used in this study was received by the end of April 1983. Appendix A lists those agencies contacted.

It was made clear in the cover material that accompanied the questionnaire, that the objective of the study was to identify present parent relief needs and in no way was intended to evaluate the effectiveness of present parent relief services.

B. Data Collection and Treatment

Handicapped children residing in the region of Halton are served by Halton, Peel, Hamilton-Wentworth and Toronto. A list was drawn up of all services and agencies known to extend services to handicapped Halton children. The Parent Relief Committee recognizes that some agencies inadvertently may have been missed.

The questionnaire was designed to be answered by professionals in the service field, thus their assessment of the need for parent relief is a professional opinion based on actual stated needs by clients/patients and professional judgement.

Of the 53 agencies issued questionnaires, 38 responded, representing a 71.7% response rate. Of these, 13 stated an inability to assess this need. Raw data was collected from 23 agencies on 482 clients.

The questionnaire was mailed in December 1982. A follow-up letter was sent to all agencies in January 1983 and at least one follow-up phone call was made to each.

In order to protect confidentiality and to allow for cross referencing in the case of two or more agencies serving the same child, clients/patients were identified by first and last initial, date of birth, and residential location (Burlington, Oakville, North Halton). Appendix B contains the questionnaire and response guide.

C. Research Considerations

Several factors must be kept in mind when contemplating the results of this study:

1. Subjectivity of Respondents

As previously stated, the data was submitted by professionals, not parents. There is always the possibility that a need perceived by service personnel is not recognized or accepted by parents. To this writers knowledge, the only agency that actually polled parents was the Oakville Association for the Mentally Retarded.

2. Inaccurate/Incomplete Data

There is always the possibility that a responding agency submitted inaccurate data (e.g. birthdates) which could result in a child not being reflected in the total figures or being reflected more than once.

a) Data on three (3) children was submitted minus birthdates; these children have not been included in the final total.

b) Trillium School submitted a total figure of forty-six (46) students who are learning disabled and benefitting from their residential program. Because students were not individually identified, these 46 children were not included in the figures used in the study.

3. Cross Referencing of Duplicate Clients

A difficulty in conducting this study was the issue of client duplication. A total of 23 agencies submitted data on 482 clients. This data was cross referenced using initials, birthdates, and living location. A second year student from Sheridan College's Research Techniques Program was responsible for this time consuming task. After cross-referencing, a total of 271 handicapped children were identified as being in need of parent relief services.

4. Currency of Data

Time devoted to this study was in addition to regular work loads of all three Case Management participants. Delays also occurred due to negotiations with the Halton Board of Education's Research Advisory Board regarding research input from school personnel. As a result, all data is relevant to January - April 1983. (see next point)

5. Halton Board of Education

The Halton Board of Education agreed, through its Research Advisory Board, to participate in the study. However, two problems arose:

- a) School personnel didn't feel they had the knowledge on which to base a response.
- b) A plan to issue questionnaires through the schools to all parents of handicapped children raised the question of potentially identifying children as handicapped (e.g. emotional problems) not previously labelled by parents or agencies/services.

It was decided not to involve the Board of Education at this point.

6. Questionnaire Design Flaw

Respondents were asked to identify the various handicaps a child has per Index Item #2 on the questionnaire. Several specific physical disabilities were keyed in addition to the key "Physically Handicapped". Thus PH was identified in addition to a specific physical handicap in some cases. When considering the number of children identified as Physically Handicapped one must bear in mind that some of these same children are reflected in the figures relevant to specific physical handicaps.

7. Lack of Agency Response

Of the agencies sent questionnaires, 17 did not respond. It is possible that some clients seen by these agencies are not receiving services from any of the agencies that did submit data.

D. Results**1. Client Identification - Table 1**

After cross referencing initials, birthdates, and home residence, a total of 271 handicapped children, ages 0-18 years, were identified as being in need of parent relief services in Halton. Of those identified, 153 (56.5%) resided in Burlington, 76 (28.0%) in North Halton, and 42 (15.5%) in Oakville. 45.4% or 123 children were in the 6-12 year age group, 32.1% or 87 comprised the 0-5 year age group, and 22.5% or 61 were 13-18 years old.

TABLE 1

<u>Home Residence</u>	<u>No.</u>	<u>%</u>
Burlington	153	56.5
Oakville	42	15.5
North Halton	76	28.0
	—	—
Totals	271	100%
<u>Gender</u>	<u>No.</u>	<u>%</u>
Male	172	63.5
Female	99	36.5
	—	—
Totals	271	100%
<u>Age Group</u>	<u>No.</u>	<u>%</u>
0 - 5 years	87	32.1
6 - 12 years	123	45.4
13 - 18 years	61	22.5
	—	—
Totals	271	100%

1. Disability/Area of Special Need - Table 2

Many children had more than one disability identified. Of the 271 children comprising the study a total of 251** were identified as having some sort of physical handicap. The next greatest area of disability was that of mentally handicapped - 131 children.

TABLE 2

<u>Handicap</u>	<u>No.</u>	<u>%</u>
* Physically Handicapped	91	33.6
! Mentally Handicapped	128	47.2
* Cerebral Palsy	54	19.9
Hyperactive	36	13.3
* Deaf	9	3.3
* Blind	19	7.0
Learning Disabled	55	20.3
Autistic	7	2.6
Emotionally Disturbed	27	10.0
* Seizure Disorder	40	14.8
<u>Other Disabilities</u>		
* Tracheotomy	1	
* Intermittant Catharization	1	
* Naso-gastric Feeding	1	
Schizophrenia	1	
Language Disability	8	
* Cystic Fibrosis	3	
! Developmentally Delayed	2	
* Microcephalic	1	
* Spina Bifida	9	
Behaviour	4	
! Happy Puppet Syndrome	1	
Aphasic	3	
* Visually Impaired	1	
* Not Specified	21	

** An inflated figure due to overlap of "PH" key and specific disability keys on questionnaire.

* Included in total figure for physically handicapped.
! Included in total figures for mentally handicapped.

3. Parent Relief Presently Being Utilized - Table 3

Family members were identified as largely meeting the needs of Parents seeking Relief from the strains of raising a handicapped child (59% or 160).

Services for mentally handicapped children were shown to meet the Parent Relief needs of 99 children (36.5%).

TABLE 3

<u>Present Relief</u>	<u>No.</u>	<u>%</u>
Family	160	59.0
Oaklands	39	14.4
Surrey Place	1	.4
Rygiel Home	4	1.5
Charlton house	8	3.0
Extend-a-Family	14	5.2
Hospital	21	7.7
Credit Valley Treatment Centre	11	4.1
B.A.M.R. Saturday Program	22	8.1
Private	28	10.3
In-Home Worker	9	3.3
<u>Other</u>		
CAS Mothers Group	1	
Woodview School	2	
Church	1	
Easter Seal Camp	5	
Ontario Crippled Children's Centre	2	
Parents	1	
CCW (School)	1	
Christopher Robin Home	1	
Integrated Day Care	1	
Recreation Dept.	1	
Sunbeam Home	1	
Grandparents	1	
School	1	
Unspecified	39	

4. Type of Parent Relief Needed - Table 4

All types of Parent Relief identified in the questionnaire index generated a high response rate. The key "Occasional Relief" was identified as needed by 147 or 54.2% of the families of handicapped children. The key "In-Home Relief" was identified as being needed by 84 or 31.0%. All other types of relief fell in-between.

TABLE 4

<u>Type</u>	<u>No.</u>	<u>%</u>
Occasional	147	54.2
Weekend	121	44.6
Vacation	85	31.4
Daily	91	33.6
In-Home	84	31.0
Out of Home	108	39.9

5. Skills Needed by Relief Provider - Table 5

The types of skills needed was questioned to determine the type of relief workers needed. The highest need was for persons skilled in Behaviour Management. A total of 138 children or 50.9% were assessed as needing this type of intervention. The next highest need identified was for personnel with homemaking skills (87 children or 32.1%) followed closely by the need for staff persons with medical training (72 children or 26.6%).

TABLE - 5

<u>Skills</u>	<u>No.</u>	<u>%</u>
Signing	9	3.3
Bliss Symbolics	6	2.2
Medical/Nursing	72	26.6
*Behaviour Management	104	38.4
Homemaking	87	32.1
<u>Other</u>		
*Behaviour Management with Life Skills Training	34	
Language Stimulation	9	
Social Skills	4	
Feeding	4	

*Combined for total figure of 138 (50.9%).

6. Agency Comments

- a) Agencies were asked if, in their opinion, Parent Relief sources in Halton are adequate to meet the need.**

Thirteen (13) responding agencies answered "No". Three (3) agencies felt too unfamiliar with resources available to comment.

- b) General comments from responding agencies noted:**

- 1. More services are needed for families of children with varying disabilities, especially services that offer a family setting (e.g. Extend-a-Family).**
- 2. Public awareness of Parent Relief needs must be promoted to create an understanding community.**
- 3. It is difficult to have Parent Relief needs for children under six years of age met in the Region of Halton.**
- 4. Most Parent Relief services are primarily for mentally handicapped children, nothing is available for families of children with the primary diagnosis of physical disability.**
- 5. No immediate services are available. Parent requesting relief now available must plan far in advance.**
- 6. There is a need for in-home Parent Relief Services. Families of "total care" children need daily support.**
- 7. Working parents require specialized day care services (before and after school) for school-aged children.**

SUMMARY

1. Professionals working with handicapped children residing in the Region of Halton have assessed 271 children between the ages of birth to 18 years as being in need of Parent Relief services.
2. The majority of parents of handicapped children (54%) presently rely on family members to meet their need for Parent Relief.
3. A need was identified for a wide variety of types of Parent Relief.
4. The skills identified as most needed by Relief providers were in the area of behaviour management, homemaking, and medical expertise.

F. RESEARCH NOTES

1. A finer analysis of the data is possible. Further statistics could be obtained by breakdowns re age groups, gender, location, disabilities, etc.
2. If it is felt that feedback through the schools is important to the legitimacy of this study, questionnaires could be distributed through the schools administration by both School Boards to the parents/guardians of ALL school children in Halton.

APPENDIX A

MAILING LIST

- * 1. North Halton Association for the Mentally Retarded
- * 2. Burlington Association for the Mentally Retarded
- * 3. Oakville Association for the Mentally Retarded
- * 4. Case Management Services
- * 5. Easter Seal Society (Hamilton)
- * 6. Halton Children's Aid Society
- * 7. Oaklands Regional Centre
- 8. Surrey Place
- 9. Halton Family Services (Acton, Oakville)
- *10. C.O.H.R. Family Services (Burlington, Milton)
- 11. Family Services, Burlington
- *12. Ontario Family Guidance Centre (Georgetown, Milton)
- *13. Children's Assessment and Treatment Centre
- 14. Ontario Crippled Children's Centre
- 15. Credit Valley Treatment Centre
- 16. Rygiel Home
- *17. Charlton House/Hamilton & District A.M.R.
- *18. Joseph Brant Memorial Hospital
- *19. Hospital for Sick Children
- *20. Oakville/Trafalgar Memorial Hospital
- *21. Chedoke Child and Family Centre/
- *22. Chedoke Cerebral Palsy Clinic
- 23. Milton General Hospital
- 24. W. Ross MacDonald School for the Blind
- *25. Canadian National Institute for the Blind (CNIB) Hamilton,
Mississauga)
- *26. Trillium School
- *27. Association for Children with Learning Disabilities
- *28. Halton Parent Infant Program
- *29. Halton Board of Education

- *30. Halton Integrated Nursery Program
- 31. Georgetown District Hospital
- *32. Milton Mental Health Clinic
- 33. Ontario Foundation for Visually Impaired Children
- *34. Halton Chronic Home Care Program
- *35. Halton Behaviour Management
- 36. Para Med Health Services
- *37. Halton Regional Health Unit
- 38. Margaret McKindley Auxiliary to the Blind
- *39. Halton Lung Association
- *40. Canadian Cystic Fibrosis Foundation
- *41. Victorian Order of Nurses
- *42. Canadian Hearing Society
- *43. Woodview Children's Centre
- *44. Canada House
- *45. Canadian Paraplegic Association
- *46. Port Nelson Project
- *47. Ministerial Associations
- *48. Multiple Sclerosis Society of Canada
- 49. Muscular Dystrophy Association of Canada
- *50. Admission, Assessment, Treatment and Discharge (AATD)
- *51. Pre-School for Hearing Impaired Students
- 52. Epilepsy Hamilton
- 53. Ernest C. Drury School
- 54. John Street Academy
- 55. Halton Separate School Board
- 56. Maycourt Children's Information Centre

*Those agencies who responded to the questionnaire.

APPENDIX B

RESPONSE GUIDE

Please read the following carefully before proceeding.

Instructions:

1. Please record the requested information for each child known to you whose special management needs are such that parents are in need of relief, whether or not relief is available or being provided.
2. Each line on the survey form is allotted to individual client. Please indicate code "keys" specified on the response index.
3. Do not hesitate to respond if certain items in the grid are unknown to you. Fill in as much as you know.
4. This survey is to ascertain needs only, and in no way will be used to evaluate current progrms.
5. Please mail completed questionnaires to:

Ms. J. Shaw
Case Management Services
Life Studies Department
Sheridan College
1430 Trafalgar Road
Oakville, Ontario
L6H 2L1

RESPONSE INDEX1. Client IdentificationClient Initial

Enter the initials of the client's first and last name only. This information will be used solely for the purpose of eliminating duplicate records on the same client by different agencies.

Client Birthdate

Enter the client's birthdate by year/month/day.

Client Sex

Enter F or M

Client's Home Residence

This item refers to the area where the child's family currently resides. Enter:

B - Burlington
O - Oakville
NH - North Halton

2. Disability/Area of Special Need

Enter each disability/problem area according to the following key:

PH - physical handicap	LD - learning disabled
MH - mental handicap	A - autistic
CP - cerebral palsy	ED - emotionally disturbed
H - hyperactive	S - seizure disorder
D - deaf	O - other
B - blind	

3. Parent Relief Presently Being Utilized

F - family/friends	CV - Credit Valley Treatment Centre
O - Oaklands Regional Centre	B - B.A.M.R. Saturday Program
S - Surrey Place	P - Private (babysitter, nanny, etc.)
R - Rygiel Home	W - In Home Worker (funded by
CH - Charlton House	Special Services at Home Program
EX - Extend-A-Family	T - Other
H - Hospital	

4. Type of Parent Relief Needed

O - Occasional	D - Daily
W - Weekend	I - In-home
V - Vacation	OH - Out-of-home

5. Skills Needed by Relief Provider

S - Signing	BM - Behaviour Management
B - Bliss Symbolics	H - Homemaking
M - Medical/Nursing	

No ____ If no, please comment:

What are your general comments & observations re: the need for Parent Relief in Halcott? Please use back of page if necessary.

Yes — No —

RESPONDING AGENCY
Name: _____

Name:

Phone:

Contact Person:

POOR

QUALITY

ORIGINAL